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ABSTRACT

This guide is intended for staff development instructors responsible for inservice education on the topic of fostering humane care for dying persons in long-term care. The introduction discusses the guide's development based on input from administrators, staff, and families of residents in long-term care facilities and focus group interviews in which more than 157 nursing staff and administrators discussed care of the dying in long-term care. Presented next is a pretest examining participant's attitudes toward and knowledge about death and dying in long-term care. Five learning modules are included: separate learning modules on managing pain and promoting comfort are presented for nurses and certified nursing assistants and modules on family and staff support in grief, spiritual needs of the dying, and communication problems. Each module contains some or all of the following: description of the module content; module objectives; content outline to be used in presentations or discussions with staff; references; and self-assessment questions. Reference lists included in 3 modules contain a total of 60 references. Concluding the guide are a posttest and a brief supplemental reading list. (MN)

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Fostering Humane Care of Dying Persons in Long-Term Care

Guidebook for Staff Development Instructors

Sarah A. Wilson, PhD. RN
Barbara J. Daley, PhD. RN

*"There is much that I have
contemplated these last few
months of my illness, but as one
who is dying, I have especially come
to appreciate the gift of life."*

Cardinal Joseph Bernardin

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Fostering Humane Care of Dying Persons In Long-Term Care

GUIDEBOOK FOR STAFF DEVELOPMENT INSTRUCTORS

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**This guidebook was prepared with funding from the
Open Society Project on Death in America.**

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List of Contributors

Sarah A. Wilson, PhD, RN, is an Associate Professor at Marquette University College of Nursing. Dr. Wilson is an anthropologist whose research focuses on adults in transition as they experience life changes and move from one stage to the next. Dr. Wilson was the principal investigator for the study *Death and Dying in Long-Term Care*. In addition, Dr. Wilson has experience as a hospice nurse.

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Chris Shaw, PhD, RN, CS, FNP, ANP is a Clinical Associate Professor at Marquette University College of Nursing. Dr. Shaw has an active primary care practice at two different clinic locations in Milwaukee. Her rich background in caring for people with cancer makes her a wonderful resource in the areas of pain and pain management.

Charles Weinrich, Chaplain, The Village at Manor Park. A Lutheran pastor, Chuck has been involved in Specialized Pastoral Care ministry for over 25 years. He is a Certified Supervisor of Clinical Pastoral Education.

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have contemplated
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Introduction

Death touches the lives of older people more than people of any other age category (Atchey, 1991). In our culture, the elderly are allowed less leeway than the young in expressing their anger and frustration over their own deaths. Death occurs among older adults in institutions more often than at home with family and friends. The portion of older adults in nursing homes increase with age, from 2% for ages 65-74 to 20% for those 85 and older (Kane, 1994). Although nursing homes were not established as sites for terminal care, they are becoming the place where many people die. Nursing home residents have a right to expect that care in the final stages of life will be directed toward promoting death with dignity and bringing life to a gentle close.

The nursing home resident comes to the nursing home as a place to live. Residents and family members assume the nursing home is an extension of the family. Nursing home residents who are in the final stages of illness expect comfort to be provided and care directed at enhancing their quality of life. Demands for greater humanization of care for the terminally ill have become more important, with increasingly elaborate medical technology and the availability of life-saving and life-prolonging procedures.

Little is known about how staff and administrators in long-term care facilities deal with the issue of death and dying. Most studies of death and dying have concentrated on the hospital as the place of death and attitudes of staff toward the terminally ill. Based on the belief that efforts directed toward providing humane care of the terminally ill must include staff, administrators, and families, the researchers conducted a series of focus group interviews with staff, administrators, and families in long-term care (LTC) facilities.

More than 157 nursing staff and administrators participated in focus group interviews to discuss care of the dying in long-term care. Participants shared their perspectives on caring for the dying in long-term care and discussed a number of issues affecting humane care of the terminally ill in long-term care. The overwhelming finding of the study was the attachment of staff to residents in long-term care. Attachment helped to facilitate a gentle closure to life. However, there are a number of mediating forces that influence the process of attachment and affect the quality of care to the dying resident. Mediating forces include individual influences, forces internal to the nursing home, and forces external to the nursing home. Individual influences impacting the quality of terminal care are caring, presence, communication, and knowledge. Forces internal to the nursing home include time, organizational values, and the environment of the LTC. Forces external to the nursing home include public perceptions of nursing homes, the changing resident population, and regulations/reimbursement. Based on analysis of mediating forces, four categories of learning needs were identified. Teaching modules were developed based on the learning needs.

We are grateful to the staff, administrators, and families who participated in the study. They helped us to learn about the sociocultural environment of long-care facilities and shed new light on the unique needs of staff and dying persons in long-term care.

Fostering Humane Care of Dying Persons In Long-Term Care

Guidebook for Staff Development Instructors

This guidebook is based on the results of a study conducted with administrators, staff, and families of residents in long-term care facilities. The purpose of the study was to identify the most pressing learning needs for staff and administrators.

This guidebook contains four teaching modules based on the learning needs identified in this study. The teaching modules included in this guidebook are:

- *Managing Pain and Promoting Comfort*
- *Spiritual Needs of the Dying*
- *Family and Staff Support in Grief*
- *Communications Problems and Solutions*

It is intended that these teaching modules be used by staff development instructors in long-term care facilities to assist meeting the identified learning needs of staff.

Each module contains:

- a description of the module contents
- module objectives
- a content outline to be used in presentations or discussions with staff
- references
- self-assessment questions to measure learning achieved

Throughout this guidebook are several case studies that were developed from this research project. The case studies can be used to facilitate staff discussions. Additionally, a pretest has been included before the modules and a posttest after the modules.

It was our intent in creating these modules to include information from the conference entitled *Death and Dying in Long-Term Care* presented at Marquette University College of Nursing on September 26, 1997.

We would like to thank the presenters at this conferences for allowing us to incorporate their teaching materials into this guidebook. Our thanks to:

Virginia Bourne, MSN, RN
Julie Griffie, MSN, RN, CS, APNP
Christine R. Shaw, PhD, RN, CS, FNP, ANP
Shelly Malin, PhD, RN
Charles Weinrich, Chaplain

We would also like to thank Rosemarie Matheus, MSN, RN, for her contribution to the spiritual module.

We hope that this guidebook will facilitate meeting learning needs of staff in long-term care as they strive to provide human care for dying residents.

Sarah A. Wilson, PhD, RN
Barbara J. Daley, PhD, RN

Death and Dying in Long-Term Care

Initial Learning Inquiry

Please take a moment to complete the following questions.

- | | | |
|--|---|---|
| 1. Attachment is a significant process that fosters care for dying persons in long-term care. | T | F |
| 2. Eighty percent of deaths in the United States occur in long-term care facilities. | T | F |
| 3. When assessing pain in cognitively impaired and cognitively intact residents, the same assessment strategies can be used. | T | F |
| 4. Unrelieved pain at the end of life can be both physical and psychological. | T | F |
| 5. Grief is a psychological, social, spiritual, and physical reaction to loss. | T | F |
| 6. Grief, following the death of a love one, is over in a few months. | T | F |
| 7. Spiritual assessment means finding out what religion the resident practices. | T | F |
| 8. Listening to the resident is the most effective method for completing a spiritual assessment. | T | F |
| 9. Communication is the basis for all human interaction. | T | F |
| 10. Active listening is usually more helpful than judging, evaluating, or advice-giving. | T | F |

Module One-A
Managing Pain and
Promoting Comfort for
Nurses

Module One-A

Managing Pain and Promoting Comfort for Nurses

Julie Griffie, MSN, RN, CS, APNP

DESCRIPTION

The purpose of this module is to assist nurses in long-term care facilities to understand both pharmacologic and nonpharmacologic strategies to the management of pain.

OBJECTIVES

1. Describe barriers to successful pain management in a long-term care setting.
2. List five pain assessment factors to consider in assessing pain in both cognitively intact and cognitively impaired residents.
3. Describe methods to deal with unrelieved pain at the end of life.

CONTENT OUTLINE

- I. Pain and Distress at the End of Life: 80% of deaths in the United States occur in institutional settings. Nurses involved in the care of dying patients have the unique opportunity to develop meaningful relationships with patients and families during the last chapter of life. In assisting patients to find meaning and express concerns, we assist in bringing a sense of closure to life.
- II. Barriers Unique to Symptom Management in Long-Term Care Settings
 - little direct physician contact
 - reliance on Certified Nursing Assistants to collect patient assessment information
 - extreme concern about state and federal regulations
 - a high incidence of cognitively impaired residents.
- III. Pain Assessment Standards
 - A. MDS
 - B. Components of assessment of cognitively intact resident: Ask your resident these questions:
 - location/locations of the pain
 - constant or intermittent
 - intensity (0-3, 0-5, 0-10, adjectives, faces)
 - quality of the pain
 - what is the history of the pain?
 - what does the resident think is the cause?
 - what makes it better?
 - what makes it worse?
 - what analgesic medications have been tried in the past?
 - what medications has the resident had in the past 24 hours for pain?
 - ★how does it affect ADLs? (This is the most important factor in long-term care. It is necessary to know the effect on daily living to develop your plan.)
 - what is the resident's goal for pain control?
(Can be "I want to be able to get out of bed to the cafeteria.")
 - C. Assessment of cognitively impaired resident
 - Behavior Change - If you see this, check diagnosis and do a physical assessment. Look for common problems listed below:
 - Discomfort Indicators
 - Incontinence
 - Hunger
 - Pressure points
 - Physical Assessment
 - Constipation, UTI, lung fields, skin breakdown, low blood sugar
 - Balance of activities

- D. Translating the assessment into a plan of care
 - Spiritual support
 - Griffie's Rule—When a pharmacological intervention is delivered for comfort, a nonpharmacologic intervention must be done simultaneously.
- E. Talking with physicians -
 - preparing to make the call -
 - checkpoints for your call—make sure to state purpose of the call, goals for the resident, and what you would like to have happen.
 - 1. Complete the assessment -
 - location/locations
 - constant or intermittent
 - intensity (0-3, 0-5, 0-10, adjectives, faces)
 - quality (i.e., burning, shooting, dully, achy)
 - what is the history of the pain/symptom?
 - what makes it better?
 - what makes it worse?
 - what analgesics or other meds have been tried in the past?
 - medications in the past 24 hours for symptom, plus other prns
 - how does it affect ADLs?
 - resident's goal for pain control/symptom management
 - 2. Discuss with colleagues—formulate a plan; what meds, dosages are appropriate for the next intervention?
 - 3. Relay 1 & 2 to the doctor; emphasize the goals of care in the discussion.
 - 4. Develop a standard form to record information and organize thoughts prior to making the call.
- IV. Unrelieved Pain at the End of Life
 - physical pain = sedation
 - psychological pain
 - examination of unresolved issues
 - healing interventions with those available
 - life review of successes
 - recognition that one has given "the best" effort toward conflict resolution
- V. Caregiver Pain/Strategies for Management of Staff Needs

Guidelines for Analgesic Drug Orders

Purpose: The following can be used as a guide for evaluating the appropriateness of analgesic orders. These guidelines are taken from the AHCPR Standards for Acute and Cancer Pain Management.

Critical Points:

1. The character (quality) of the pain has been documented on assessment (e.g., burning/shooting pain) so that the health care provider can determine the type of pain (e.g., neuropathic pain).
2. The oral route is the first choice for analgesic orders. If a patient is unable to take po medications, buccal, sublingual, rectal, and transdermal routes are considered before intravenous or subcutaneous routes.
3. Patients who report constant moderate to severe pain receive a long-acting medication and have a short-acting medication ordered prn for breakthrough pain.
4. Patients who report intermittent pain have medications ordered on a prn basis.
5. Only one combination analgesic (opioid and nonopioid, e.g., Vicodin, Tylenol #3) is ordered for prn breakthrough pain.
6. Only one opioid is ordered for continuous moderate to severe pain (e.g., MS contin, Oramorph SR, Kadian, Oxycontin, or duragesic).
7. Short-acting oral opioids are ordered at intervals **no longer** than 4 hours (see below).
8. Dose escalations are calculated as a percentage of the current dose, based upon the patient's pain rating. A rough guideline, assuming normal renal function is:
 - pain rated as 3-6/10, dose escalation is 25-50% of current dose
 - pain rated as 7-10/10, dose escalation is 50-100% of current dose
9. The frequency of dose escalation is dependent on the opioid preparation in use. Guidelines for dose escalation for **oral/rectal/transdermal opioids** are (assuming normal renal function). Doses can be safely escalated:
 - Every 1-2 hours—short-acting oral/rectal products:
Morphine, oxycodone, hydromorphone
 - Every 24 hours—long-acting oral opioids:
MS Contin, Oramorph SR, Oxycontin
 - Every 48-72 hours:
Duragesic Patch, methadone, levorphanol

10. Prescribe adjuvant analgesics for opioid nonresponsive neuropathic pain.
11. An appropriate plan for a bowel regimen is ordered to prevent constipation.
12. A plan is in place for a pharmacological and/or a nonpharmacological analgesic intervention prior to activities that are reported to cause or increase pain.
13. A pain management flow sheet is initiated on all patients rating pain as moderate (e.g., $\geq 5/10$, $\geq 3/5$, or $\geq 2/3$) on admission.
14. Orders for nonpharmacological interventions are present and are clearly stated as part of the analgesic plan.
15. Demerol use is restricted to short-term, procedure-related pain, of duration less than 48 hours.

Sources:

1. Acute Pain Management Guideline Panel. Acute Pain Management: Operative or medical procedures and trauma. Clinical Practice guideline. AHCPR Pub. No. 92-9932. Rockville, MD: Agency for Health Care Policy and Research, Public Health Service, U.S. Department of Health and Human Services, February 1992.
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American Nurses Association

Position Statement on Promotion of Comfort and Relief of Pain in Dying Patients

Summary: Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient. The increasing titration of medication to achieve adequate symptom control, even at the expense of life, thus hastening death secondarily, is ethically justified.

Nursing has been defined as the diagnosis and treatment of human responses to actual or potential health problems (American Nurses Association, 1980). When the patient is in the terminal stage of life when cure or prolongation of life in individuals with serious health problems is no longer possible, the focus of nursing is on the individual's response to dying. Diagnosis and treatment then focuses on the promotion of comfort which becomes the primary goal of nursing care.

One of the major concerns of dying patients and their families is the fear of intractable pain during the dying process. Indeed, overwhelming pain can cause sleeplessness, loss of morale, fatigue, irritability, restlessness, withdrawal, and other serious problems for the dying patient (Amenta, 1988; Melzack, 1990; Spross, 1985). Nurses play an extremely important role in the assessment of symptoms and the control of pain in dying patients because they often have the most frequent and continuous patient contact. In planning nursing care of dying patients, "the patient has a right to have pain recognized as a problem, and pain relief perceived by the health care team as a need" (Spross, McGuire, & Schmitt, 1990).

The assessment and management of pain should be based on a thorough understanding of the individual patient's personality, culture and ethnicity, coping style, and emotional, physical, and spiritual needs, and on an understanding of the pathophysiology of the disease state (Dalton & Fenerstein, 1988). The main goal of nursing intervention for dying patients should be maximizing comfort through adequate management of pain and discomfort as this is consistent with the expressed desires of the patient. Toward that end, the patient should have whatever medication, in whatever dosage, and by whatever route is needed to control the level of pain as perceived by the patient (Wanzer et al., 1989).

Careful titration of pain medication is essential to promote comfort in dying patients. The proper dose is "the dose that is sufficient to reduce pain and suffering" (Wanzer et al., 1989). Tolerance to pain medications often develops in patients after repeated and prolonged use. Thus, both adults and children may require very high doses of medication to maintain adequate pain control. These doses may exceed the usual recommended dosages of the

particular drug for patients of similar age and weight (Eland, 1989; Foley, 1989; Inturrisi, 1989; Schmitt, 1990).

While it is well known that pain medications often have sedative or respiratory depressant side effects, this should not be an overriding consideration in their use for dying patients as long as such use is consistent with the patient's wishes. The increasing titration of medication to achieve adequate symptom control, even at the expense of maintaining life or hastening death secondarily, is ethically justified. The nurse assumes responsibility and accountability for individual nursing judgments and actions (American Nurses Association, 1985). Nurses should not hesitate to use full and effective doses of pain medication for the proper management of pain in the dying patient.

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Adopted by: ANA Board of Directors

Related Past Action: 1. Code for Nurses with Interpretive Statements, 1985
2. Position Statement on Nurses' Participation in Capital Punishment, 1988

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SELF-ASSESSMENT QUESTIONS

Mrs. B, a 75-year-old patient with a history of S/P hip replacement, osteoporosis, and pneumonia, has been a resident at your facility for four months. Since her hospitalization three weeks ago for treatment of pneumonia, she has clearly stated that her goal is not to return to the hospital—no further IV antibiotics, no blood tests, no CPR—Comfort Measures only. She speaks openly of death and believes it will come soon. She adds to this statement that she is a little frightened.

List three areas for potential nursing diagnoses.

- 1.
- 2.
- 3.

You are working as PM Supervisor. The staff calls you and tells you that Mrs. B is confused and refuses to get out of bed for dinner. What information would you expect to receive in the assessment report?

You arrive to see Mrs. B and find her febrile, confused, and refusing to move in her bed. You obviously need to contact the physician (and family). What are your goals of this contact?

Module One-B
Managing Pain and
Promoting Comfort for
CNAs

Module One-B

Managing Pain and Promoting Comfort Certified Nursing Assistants (CNAs)

Christine R. Shaw, PhD, RN, CS, FNP, ANP

DESCRIPTION

The purpose of this module is to assist CNAs to understand their role in pain management.

OBJECTIVES

Upon completion of this module, the CNA will be able to:

1. Define pain as experienced by long-term care residents.
2. Describe the reasons for differences in pain expression by people with different illnesses and different backgrounds.
3. Explain how pain affects other elements of life.
4. Discuss how pain medications work to relieve pain and how they affect safety of the patient.
5. Discuss the importance of non-drug treatments in helping to relieve pain.
6. Value the role of the CNA in relieving the patient's pain.

CONTENT OUTLINE

- I. Pain—An Overview of How It Works
 - A. "What makes a person feel pain?"
 1. Triggers of pain (heat, cold, trauma, etc.)
 2. Pain messages through nerve endings
 3. Pain messages up spine to brain
 4. The meaning of pain from the brain
 - B. Definition—"Pain is whatever the patient says it is whenever the patient says it is" (1979, Margo McCaffrey, *Nursing Management of the Patient in Pain*).
 1. What does this mean to the caregiver?
 2. What does this mean to the resident?
- II. Appearances of People in Pain
 - A. "She doesn't look like she's in pain"
 1. Acute pain (increased BP, P, R, agitated, looks in pain)
 2. Chronic pain (no change in vital signs, can sleep, doesn't look like in pain)
 3. Pain changes the quality of life
 - B. "I show pain the way my family taught me to"
 1. Personal expressions of pain
 2. Cultural expressions of pain
 3. Beliefs about pain control
 - a) Meaning of suffering
 - b) Beliefs about pain medications
- III. How Pain is Relieved
 - A. How medications work to relieve pain
 1. Narcotics (morphine, codeine, fentanyl)
 - a) not usually used for chronic pain except in cancer
 - b) works in brain to change people's perception of pain
 - c) side effects (constipation, dizziness/sleepiness, slowed breathing)
 - d) What about addiction?

2. Non-narcotics (acetaminophen [Tylenol], aspirin, ibuprofen [Advil, Motrin], naproxen [Aleve])
 - a) used alone or with narcotic
 - b) works on the nerve endings
 - c) side effects (stomach upset—even ulcers, dizziness, water weight gain)

B. Other Ways to Relieve Pain

1. Massage
2. Heat
3. Cold
4. Ointments (Ben Gay, Icy-hot, Capsalgin P/Zostrix)
5. Positioning
6. Distraction
7. Relaxation
8. Imagery
9. Other
 - a) TENS (transcutaneous electrical nerve stimulation)
 - b) Injections/nerve blocks
 - c) Hypnosis
 - d) Acupuncture/acupressure

IV. Your Role in Assisting the Patient with Pain

Recommended reading: McCaffrey, M., & Beebe, A. (1989). *Pain: Clinical manual for nursing practice*. C.V. Mosby Co.

SELF-ASSESSMENT QUESTIONS

1. List three symptoms of pain:
 - a)
 - b)
 - c)
2. Describe one example from your work setting of a cultural expression of pain.
3. List three ways CNAs can help relieve a resident's pain:
 - a)
 - b)
 - c)

Module Two
Family & Staff
Support in Grief

Module Two

Family and Staff Support in Grief

Virginia Bourne, MSN, RN

DESCRIPTION

The purpose of this module is to assist staff in long-term care facilities understand the grieving process of residents and families. Additionally, staff will discuss interventions designed to assist the grieving person.

OBJECTIVES

1. Describe the grief process.
2. List reasons for grieving.
3. Discuss the symptomatology of grief.
4. List interventions to assist the griever.

CONTENT OUTLINE

- I. Definitions
 - A. Grief is an attempt to get things back together after a loss
 - B. Grief is the price we pay for love
 - C. Grief is the psychological, social, spiritual, and physical reactions to a loss
 - D. Grief is not logical
 - E. Period of grief depends on length and depth of attachment
 - F. Different cultures grieve different ways
- II. Types of Grief
 - A. Anticipatory Grief
 - 1. Loved one preparing for the loss
 - 2. Still expresses hope
 - B. Acute Grief
 - 1. The person has died
 - 2. The loved one no longer has hope of survival
- III. Events Precipitating a Grief Reaction
 - A. Events in our lives—moving an elderly relative to live with you or to a nursing home
 - B. Losses in our lives—loss of family member or friend, death of pet
- IV. Symptoms of Grief
 - A. Feeling tight in the throat
 - B. Sighing
 - C. Short of breath
 - D. Empty feeling in stomach
 - E. Lose strength (because grief is tiring work)
 - F. Energy levels down
 - G. No appetite
 - H. Sleep disturbances
 - I. Grieving person feels cold
 - J. May assume symptoms of the person who dies
 - K. Lose interest in life
 - L. Difficulty concentrating
 - M. Feel mental pain
 - N. Feel helpless
 - O. Feel guilt
 - P. Anger
- V. Interventions Enabling One to Grow Through Grief
 - A. Allow the grieving person to talk about it again and again and again
 - B. Recognize grief is individual response
 - C. Encourage family members to vent emotions by painting, writing in a journal, composing poems or singing gospel hymns
 - D. Don't be afraid to cry
- VI. Caring for Oneself and Our Co-Workers

A Grief Shared Is a Grief Diminished

You Do Not Grieve to Forget—You Grieve to Remember

Staff members may be unsure what to say to family members who have recently experienced a loss. Watson (1994) offers the following practical suggestions:

Avoid:	Try:
I know how you feel.	Tell me how you feel.
He/she lived a full life.	How can I help?
Life must go on.	This must be very painful.
God had a purpose. It was a blessing.	This must be hard to accept.
Time makes it easier.	How are you doing?

It is important to convey to the family that staff recognize the loss and show concern for the family member.

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The following resource is available from the National Kidney Cancer Association at no charge. It is written by a physician who is dying from renal carcinoma and is an excellent resource.

National Kidney Cancer Association
1234 Sherman Avenue, Suite 203
Evanston, IL 60202-1375
847-332-1051

Bone, Roger, C. (1977). Reflections: A Guide to End of Life Issues for You and Your Family. National Kidney Cancer Association.

Relaxation and Stress Reduction Exercises

Stress is part of life and is a response to changes that you must adjust to. Sources of stress may be the environment, your body, or your thoughts. The response to stress may be decreased by learning to relax. Stress reduction exercises are easy to perform and can be done at your convenience. The exercises need to be practiced over a period of time to be of benefit. Try to set aside time every day for relaxation and stress reduction. Examples of some exercises for body awareness, breathing, progressive relaxation, and mediation are given below.

Body Awareness

The purpose of body awareness exercise is to help identify sources of stress. The importance of body states and their relationship to stress have been studied for centuries by eastern philosophies such as Zen and Yoga. The mind-body relationship is based on the fact that the body is aware of stress before the conscious mind. Muscle tension is the body's way of letting you know you are under stress. One exercise to become aware of body stress is Letting Go.

Letting Go

Lie down on a rug and get comfortable. Bend your knees until your feet are flat on the floor. Close your eyes. Stay in a comfortable position, move if necessary to get comfortable. Become aware of your breathing. Feel the air come in your nose, mouth and down your throat into your lungs. Focus on all your body parts. What parts come into awareness first? What parts are you less aware of? Do you experience any discomfort? Become aware of the discomfort until you can describe it. Let your body take over. Be aware of what happens to the discomfort. Practice this for five or ten minutes every day.

Breathing

Proper breathing is essential for health and may be an antidote to stress. Breathing exercises are easy to learn and some benefits may be apparent immediately. Long benefits of breathing exercises will become noticeable after months of practice. Exercises for deep breathing, a relaxing sigh, and purifying breath are given below.

Deep Breathing

Lie down on a rug for this exercise. Bend your knees and move your feet apart approximately eight inches. Turn your toes outward slightly. Keep your spine straight. Check your body for tension.

Place one hand on your abdomen and one hand on your chest. Inhale slowly through your nose to your abdomen to push your hand up. Your chest should move a little with your abdomen. When you are comfortable with this, smile slightly and inhale through your nose and exhale through your mouth. Blow out gently making a sound like the wind. Take slow, long, deep breaths to raise and lower your abdomen.

Do deep breathing 5 or 10 minutes once or twice a day for two weeks. Extend the time if you wish.

When you finish deep breathing check your body again for tension. As you become more at ease doing deep breathing you may try it sitting up.

Relaxing Sigh

Sighing or yawning is a sign you are not getting enough oxygen. It's your body's way of correcting this. A sign is often accompanied by a feeling that things are not quite as they should be. A sigh may be helpful in releasing tension.

Stand up or sit up in a chair. Sigh deeply, letting out a sound of relief as the air rushes out your lungs. Let the air come in naturally, do not think about inhaling. Do this 10-12 times, or whenever you feel the need for it.

Purifying Breath

This exercise tones up your body and breathing. Start by sitting up or standing up in a straight position. Inhale for a complete natural breath. Fill the lower section of your lungs. Then fill the middle part of your lungs as your lower ribs and chest move slightly forward. Fill the upper part of your lungs as you raise your chest slightly and draw in your abdomen. Hold this breath for a few seconds.

Exhale a small amount of air through your lips, like you are blowing through a straw. Stop exhaling for a few moments, then blow out more air. Continue this until all the air is exhaled in small, forceful puffs.

Mediation

Mediation is a means of decreasing inner tension and increasing self-knowledge. It helps you to focus uncritically on one thing at a time. Mediation has been described as a form of self-discipline and increases self-esteem. the following components are important for mediation:

- Find a quiet place where you are not distracted.
- Select a comfortable position that you can hold for 20 minutes.
- Select an object to dwell on, such as a word or sound.
- Maintain a positive attitude. Let go of thoughts and feelings.

Establish your posture.

Select a comfortable sitting position. The position may be (1) in a chair with your arms and legs relaxed, (2) cross-legged on the floor, (3) Japanese fashion on your knees with big toes touching and your heels pointed outward so that your buttocks is resting on your feet, and (4) Yoga lotus position—this requires practice and conditioning.

Scanning Your Body for Tension

Feet and legs—Wiggle your toes, rotate your feet and relax them. Note any tension in your calves.

Lower torso—Be aware of tension or pain in lower back and relax. Note any tension in hips, back, and buttocks. Try to relax these areas.

Diaphragm and stomach—Take a couple deep breaths, breath in and out slowly. Be aware of any tension in this area.

Lungs and chest—Be aware of any tension in this area. Relax and take a couple slow deep breaths.

Shoulder, neck, and throat—Swallow and notice any tension in throat or neck. Roll your head around clockwise a few times and then counterclockwise. Shrug your shoulders a couple of times and be aware of any tension.

Head—Start at the top of your head and scan for tension. Look for pain in your forehead or behind your eyes. Note any tightness in your jaw. Be aware of your ears. Go back over your head and relax each part.

Scan entire body—Be alert for any tension and relax deeper and deeper.

Breath Counting Meditation

This is one of the most popular forms of mediation and is effective for deep relaxation and self-discipline. Select a quiet place and center yourself. Chose a position and scan your body for tension. Close your eyes or gaze at a spot on the floor. Breath through your nose. Inhale, exhale and pause. Say "one" when you exhale and continue to breath in and out saying one each time you exhale.

Try doing this for 10 to 20 minutes at a time. When you get distracted by other thoughts, focus on saying one as you exhale. When you finish breathing exercise, sit quietly with your eyes closed. Focus. Experience your thoughts and feelings. Open your eyes and sit for a few minutes appreciating the effects of mediation. Practice this exercise five times or more a week. You should do this exercise for at least one month before deciding to continue or give it up.

The above are some examples of stress relaxation techniques. Several other methods are available such as listening to music and deep breathing, and imagery. Your local library or bookstore may be a source for information on relaxation techniques.

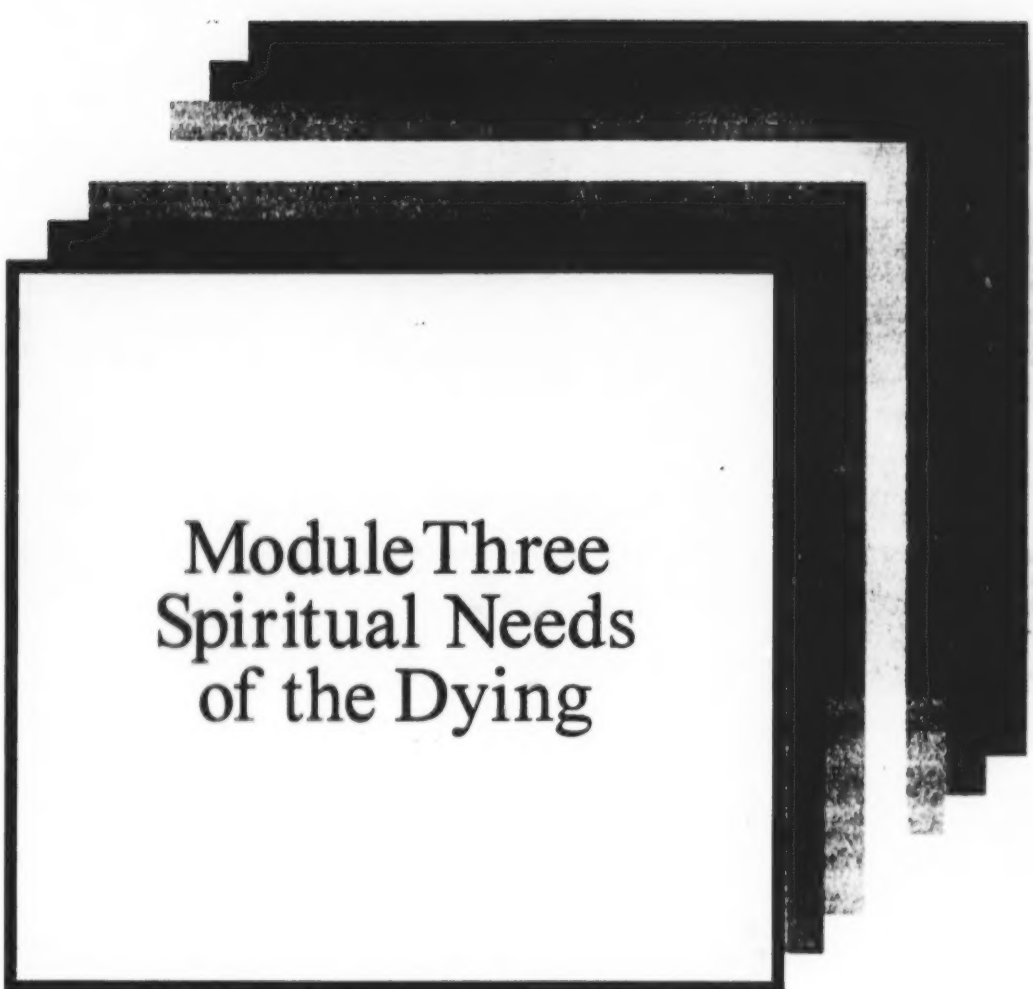
Source: Davis, M., Eshelman, E., & McKay, M. (1982). *The relaxation and stress reduction workbook* (2nd ed.). Oakland, CA: New Harbinger Publications.

SELF-ASSESSMENT QUESTIONS

1. Define grief.
2. List 3 reasons to grieve.
3. True or False: Grief is over in a few months.

Answers:

1. Grief is a psychological, social, spiritual, physical reaction to a loss.
2. Loss of a loved one
Loss of a job
Loss of health
Loss of physical/intellectual abilities
Loss of belongings
3. False.

A decorative graphic consisting of several overlapping black rectangles of varying sizes, creating a stepped, layered effect. The rectangles are positioned on the right side of the page, with the largest one at the top and smaller ones stacked below it, partially obscuring the text area.

Module Three Spiritual Needs of the Dying

Module Three

Spiritual Needs of the Dying

Rosemarie Matheus, MSN, RN
and
Charles Weinrich, Chaplain

DESCRIPTION

The purpose of this model is to assist staff in long-term care facilities in meeting the spiritual needs of dying persons, to value each person as a unique individual with his/her own belief system, and to explore interventions for spiritual care.

OBJECTIVES

1. Describe what spirituality means to self and resident.
2. Differentiate between spirituality and religion.
3. Explain what is meant by spiritual well-being.
4. Identify signs of spiritual distress (feeling of hopelessness, powerlessness, or fear of not having led a meaningful life).
5. Describe interventions that may be used to assist residents in coping with multiple losses (life review, reminiscence, pray, relaxation, music, guided imagery).
6. Respect resident's belief systems and treat every resident as a unique person.

CONTENT OUTLINE

- I. What is Spiritual Care?
 - A. What it means to the client, what it means to the caregiver
 - B. What does it include?
 - C. One's relationship with God, Ultimate Other, etc.
 - D. One's relationship with others
 - E. Has a different focus and scope than the term "psychosocial"
- II. Ability and Comfort of the Caregiver to Give Spiritual Care
 - A. Caregiver's feelings about own death and death of others
 - B. Caregiver's comfort level in verbalizing spiritual issues
 - C. Caregiver's view of the value of spiritual care as appropriate
- III. Assessment of the Spiritual Needs of the Hospice Client
 - A. Inclusion of all clients, not just those identified as "religious"
 - B. What to assess:
 1. Client's relationship with God
 2. Client's definition of God
 3. Client's need for reconciliation/forgiveness
 4. Client's need to complete "unfinished business" (add here things client may want to say to family member)
 5. Client's desire/request for religious articles/practices
 6. Client's use of prayer/meditation/rituals
 - C. Family's spiritual needs
 - D. Spiritual assessment cannot be done until client has a trust relationship with the caregiver
 - E. Listening to the client is the *MOST* effective method of assessing for spiritual needs
 - F. Direct questioning is not often appropriate/written forms are NOT appropriate
 - G. Spiritual needs often are entwined with the physical and mental statements and behaviors and concerns of the client and family
- IV. Suggested Interventions for Providing Spiritual Care
 - A. Allowing time, planning time, honoring the time as necessary as bathing, medicating, etc.
 - B. Therapeutic presence
 - C. Touch
 - D. Facilitating needs for religious contacts/practices—connection with clergy
 - E. Use of music, prayer, readings
 - F. Address unfinished business
 - G. Find a way to pass the baton. If a resident has always wanted to do something, help them find a way that friends or family can help.
 - H. Use religious resources
 1. Bible
 2. Religious history of person
 3. Hymns
 4. Prayer

V. Understanding Spiritual Needs

Three basic spiritual needs have been defined as:

- A. To see oneself as a person of worth and value
- B. To love and be loved
- C. To have meaning and purpose in life

Use the matrix below to analyze, when the resident is expressing this need, what type of response to make and suggestions that can be added to their care.

Need	Danger Sign	Response	Suggestions
A. Person of Worth			
B. Love and be Loved			
C. Meaning and Purpose			

(Suggested responses next page).

Need	Danger Sign	Response	Suggestions
A. Person of Worth	Person says, "I can't even get dressed." "I have made a mess of my life." or example of person who arranges to get ignored	"God loves you." "I like you just the way you are."	Address residents with their names to confirm value and worth. Spend time. Find tasks the resident can do.
B. Love and be Loved	People who are lonely	Express feelings to resident	Help them recall memories of being loved.
C. Meaning and Purpose	Not being able to do what they used to "Why am I still here?"	Convey that resident did and does make a difference. "You have let me journey with you." Part of the gift I get is letting me take care of you and experience you as a person."	Have them pray for others.

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Listening As Healing

*When I ask you to listen to me
And you start giving advice you have not done what I ask.
When I ask you to listen to me
and you begin to tell me why I shouldn't feel that way, you
have failed me, strange as that may seem.
Listen—all I ask is that you listen—not talk or do—
Just hear me. You're trying to cure me, not hear me.
The giving of advice can never take the place of
giving of yourself. I'm not helpless or hopeless . . .
When you do something for me that I can and need
to do for myself, you contribute to my fear and weakness.
But when you accept as a simple fact that I do feel
what I feel, no matter how irrational that may seem to you,
then I quit trying to convince you and can get about the
business of understanding what's behind this irrational feeling.
And when that's clear, the answers are obvious,
and you know what . . . your listening made that possible.
Irrational feelings make sense when we understand what's
behind them.
Perhaps that's why prayer works, sometimes, for
some people because God is still and doesn't give advice or try
to fix things. God just listens and lets you work it out yourself,
staying your silent partner.
So, please listen and just hear me . . . and we can
both keep in mind that there are important times in our lives
when we just need to be heard, not cured.*

**Reprinted with permission from "Pastoral Cares" newsletter of
Pastoral Counseling Service of Greater Milwaukee.**

Guidelines for Helping Persons Experience Their Own Spirituality

1. Know yourself as a spiritual being. What gives your life meaning? What is especially frightening?
2. Remember that being aware of the presence of God does not depend on being able to define or describe God.
3. Remember that each person is the expert about one's own path. It is then that we can explore their uniqueness.
4. Understand spiritual assessment as an ongoing process within the context of a relationship.
5. Be aware that the need to be with and to bear painful feelings is as significant and important as the need to do and to do for persons experiencing spiritual distress.
6. Help the person and yourself find goals, hope, and pleasure for the present moment.
7. Encourage reminiscing and share in life review, a process during which persons remember and often resolve or understand old pain and conflicts from a new perspective.
8. Allow persons to grieve for themselves and those around them.
9. Know that by being present we can decrease the separation and aloneness which persons often fear.
10. Remember and know that you are helping a person toward wholeness—in the moment—now—even when pain and limitation are part of the moment.

Source: Reprinted with permission from "Dealing with Spiritual Concerns of Clients in the Community" by M. Burkhardt and M. G. Nagai-Jacobson, American Holistic Nurses Association Annual Conference, June 1987.

SELF-ASSESSMENT QUESTIONS

Maude James is an 84-year-old nursing home resident with a terminal illness. She realizes that she does not have much longer to live and is concerned about her family, especially her daughter Sarah. Maude was very angry with Sarah when she was admitted to the nursing home; she thought Sarah could have cared for her at home. Sarah realizes her mother was upset with the decision for nursing placement, but it does not make it any easier to accept. She feels guilty about making the decision, and both avoid talking about the subject.

Questions:

Maude mentions to you that she does not have much longer to live and is concerned about her daughter Sarah. She comments: "It was difficult for me to come here; I was annoyed with Sarah for suggesting it. We have never talked about it; it's been too upsetting." How would you respond to Maude? What would you suggest?

Ethel Brown is a 79-year-old Black woman with a diagnosis of lung cancer. She is on oxygen because she gets short of breath with any activity. Ethel has been in Stonebrook Nursing Home for two months. She has become increasingly short of breath in that time and states she has no energy to do anything. Ethel has two married daughters who visit once or twice a month. Ethel stays in her room most of the time. The nurses have tried to encourage her to be out of the room for meals and some activities.

Ethel tells the nursing assistant who has been caring for her that she knows she is going to die, and she is scared. She questions why God is making her suffer and is angry that this is happening to her. Ethel used to read her bible every day, but her eyesight is so poor she has not been able to do so for some time. She questions: What good will it do anyway?

Questions:

Is Ethel experiencing spiritual distress?

What are some indicators of spiritual distress?

How could you help Ethel? What interventions might be helpful?

Module Four
Communication
Problems

Module Four

Communication Problems:

Moving Toward Effective Solutions in Tough Situations

Shelly Malin, PhD, RN

DESCRIPTION

The purpose of this module is to assist staff in long-term care settings to be able to analyze their own communication strategies and to select effective strategies for use with common situations in long-term care.

OBJECTIVES

Upon completion of this module, the participant will:

1. Describe effective communication techniques.
2. Practice active listening with residents.
3. Select communication strategies to use in long-term care settings.
4. Describe processes for dealing with anger.

CONTENT OUTLINE

I. Communication Basics

A. Communication is the basis for all human interaction

1. It only takes one person to change a relationship—YOU or ME
2. The leverage for change in communication is within me—***I CAN ONLY CHANGE ME***
3. If the communication strategies you are trying aren't working, try something else.
4. Nothing works all of the time.

B. Effective Communication

1. "I" messages.
2. Be concrete and specific.
3. Verbal and nonverbal should be congruent
4. Ask for feedback.
5. Describe your feelings.
6. Describe others' behavior without evaluating.

C. Problem Ownership

Whose problem is it . . . Yours or Mine?

D. Communicating When the Problem is Yours

1. "I" Messages
 - ☆ take responsibility
 - ☆ do not pass judgment or assign blame
 - ☆ simply communicate honest feelings
2. Benefits of "I" Messages
 - ☆ clear communication
 - ☆ doesn't push other to defensiveness
 - ☆ usually you feel relieved after communicating feelings

WATCH OUT FOR DISGUISED MESSAGES

Down side

No guarantee that it will result in the problem being solved

3. Awareness Wheel: What am I sensing, thinking, feeling, wanting to do, and then doing?

E. Communicating When the Problem is Theirs

1. **Active Listening**, usually more helpful than evaluating, judging, advice giving
2. May help with problem solving if you want to

F. Attitudes for Active Listening

1. Must **want** to listen.
2. Must **want** to be helpful.
3. Must be able to **accept** others' feelings
4. Must have deep **trust** in other's capacity.
5. Accept feelings are transitory.
6. Accepting of self. (T. Gordon L.E.T.)

II. Common Tough Situations in Long-Term Care

A. Communicating with families when a resident is dying (Scenario 1)

- ☆ Giving information over the telephone
- ☆ *What is the right thing to say?*
- ☆ Demonstrating authentic caring
 - attention to physical environment
 - coming and going from the room
- ☆ Helping family do what they want to do
- ☆ At the time of death
- ☆ Supporting each other

B. Helping families decide about options (Scenario 2)

- ☆ Active or empathetic listening
- ☆ Weighing pros and cons
- ☆ *What about when they want to know what you would do?*

III. Dealing with Anger . . . Theirs, Yours, and Ours (Scenario 3)

1. Center, breathe, THEN talk
2. Give yourself an out
3. Avoid defensiveness
4. Understand expectations
5. Set deadlines

SELF-ASSESSMENT QUESTIONS

Scenario 1: Communication When A Person Is Dying

Mary Jones is an 89-year-old woman who is dying in your facility. She has been becoming less responsive over the last 2-3 hours (it is now 0200), and you wonder if you should call her family to come in and be with her.

1. How will you decide?
2. Write out an opening script for the call.

Make the call (family member, nurse).

You are the nursing assistant on the day shift who is taking over. Mary is doing worse, and many family members have gathered in the room. You don't know the family or Mrs. Jones very well.

1. What do you want to communicate on first entering the room?
2. Write out an opening script.
3. Now look at it to see if it meets the requirements for effective communication.

Mr. Earl Black has lived at Good Shepherd Long-Term Care Facility for the past five years. Mr. Black has lived with cancer for the past year. His condition has worsened, and the cancer has metastasized throughout his body. Last week he and his family decided it would be best to stop all treatment and provide palliative care only. This morning he is in a confused, semi-alert state. His blood pressure, pulse, and respirations are elevated and temperature is 101. Mr. Black has a durable power of attorney and living will which both state he does not wish to be kept alive with artificial measures, including fluids, food, antibiotics. His daughter and son are called and come in to see him and decide how to proceed. They don't know if their father should be transferred to the hospital for work-up and treatment or remain at Good Shepherd.

1. What is your role with this family?
2. What is your goal with this family?
3. Who else should be included in a discussion with the family?

Scenario 3: Dealing with Anger . . . Theirs, Yours, and Ours

You are having the proverbial "shift from hell," a very busy pm shift with two staff calling in sick, one resident "going down the tubes" and you can't even figure out how to get time to go to the bathroom. A family member (that you have never seen before) visiting Genevieve Snow finds you and begins yelling "I'm Mrs. Snow's grandson and I want someone in her room immediately. I found her in bed, wet and smelling because she said she called to go to the bathroom but no one came to help her. I want someone now. I can not believe how poor the care is here!"

As far as you know this man has never been to see Mrs. Snow in the five years she has lived in your facility. You know that Mrs. Snow, who has Alzheimer's disease is confused and frequently incontinent and you took her to the bathroom yourself less than an hour ago.

This is a situation that could easily "push your buttons."

1. What is your goal in communicating with this family?

2. Write out an opening script.

3. Now check it for defensiveness and anger.

Death and Dying in Long-Term Care

Final Learning Inquiry

Please take a moment to complete the following questions.

- | | | |
|--|---|---|
| 1. Attachment is a significant process that fosters care for dying persons in long-term care. | T | F |
| 2. Eighty percent of deaths in the United States occur in long-term care facilities | T | F |
| 3. When assessing pain in cognitively impaired and cognitively intact residents, pretty much the same assessment strategies can be used. | T | F |
| 4. Unrelieved pain at the end of life can be both physical and psychological. | T | F |
| 5. Grief is a psychological, social, spiritual, and physical reaction to loss. | T | F |
| 6. Grief, following the death of a love one, is over in a few months. | T | F |
| 7. Spiritual assessment means finding out what religion the resident practices. | T | F |
| 8. Listening to the resident is the most effective method for completing a spiritual assessment. | T | F |
| 9. Communication is the basis for all human interaction | T | F |
| 10. Active listening is usually more helpful than judging, evaluating, or advice-giving. | T | F |

SUPPLEMENTAL READING LIST

Fostering Humane Care of Dying Persons in Long-Term Care

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